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CHILDREN'S BUREAU ACTIVITIES IN MENTAL RETARDATION.
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A HISTORY OF THE CONCERN FOR MENTALLY HANDICAPPED CHILDREN BY THE CHILDREN'S BUREAU IS FOLLOWED BY DESCRIPTIONS OF ITS VARIOUS PROGRAMS. HEALTH SERVICES INCLUDE APPROPRIATION OF FUNDS FOR SPECIAL PROJECTS SERVING THE MENTALLY HANDICAPPED, PERSONNEL TRAINING THROUGH GRANTS TO UNIVERSITIES, GRANT PROGRAMS FOR MATERNITY AND INFANT CARE PROJECTS, AND SUPPORT OF SCREENING, DETECTION, AND TREATMENT PROGRAMS RELATED TO PHENYLKETONURIA. MULTIPLY HANDICAPPED RETARDED CHILDREN RECEIVE SPECIAL CLINICAL PROGRAM FUNDS. THE CHILD WELFARE SERVICES PROGRAM AUTHORIZES FUNDS FOR PARENT COUNSELING, HOMEMAKER SERVICES, FOSTER FAMILY CARE, ADOPTIVE SERVICES, AND OTHERS. A STAFF DEVELOPMENT AND TRAINING PROGRAM PROVIDES TUITION AND MAINTENANCE GRANTS FOR EDUCATIONAL LEAVE FOR CHILD WELFARE PERSONNEL. STATE AND LOCAL EFFORTS TO EXPAND AND IMPROVE THEIR SERVICES TO THE MENTALLY HANDICAPPED ARE STIMULATED AND ASSISTED BY THE BUREAU IN THE DEVELOPMENT OF GUIDES AND PROGRAM MATERIALS, CURRICULUM PLANNING, COORDINATION OF SERVICES, AND OTHER CONSULTATIVE SERVICES. GRANTS ARE AVAILABLE FOR RESEARCH AND DEMONSTRATION PROJECTS OF REGIONAL OR NATIONAL SIGNIFICANCE OR WITH NEW METHODS AND FACILITIES. STUDIES THAT SHOW PROMISE OF MAKING A SUBSTANTIAL CONTRIBUTION TO THE ADVANCEMENT OF HEALTH PROGRAMS FOR MOTHERS AND CHILDREN ARE ALSO SUPPORTED. FUTURE PLANS INCLUDE SUPPORT FOR THE PREVENTION OF RETARDATION, EXPANSION OF COMMUNITY PROGRAMS, CLINICAL CENTERS, GENETIC AND BIOCHEMICAL LABORATORY SERVICES, AND ADDITIONAL TRAINING PROJECTS FOR PROFESSIONAL AND SUBPROFESSIONAL WORKERS. (RS)

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Children's Bureau Activities in MENTAL RETARDATION

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Children's Bureau Activities in MENTAL RETARDATION

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Concern for mentally retarded children by the Children's Bureau stems initially from its responsibility under the Basic Act of 1912 to "investigate and report on all matters pertaining to the welfare of children and child life." In the first 6 years of its existence, three of the major studies produced by the Bureau dealt with mental retardation.

With the passage of the Social Security Act of 1935, the Bureau was given the added responsibility of administering Federal grants for maternal and child health, crippled children, and child welfare services. The act emphasized the principle that the Federal Government shares with the State and local governments the responsibility for helping provide community services children need for a good start in life. It also afforded the Bureau an opportunity to help the States develop demonstrations and special programs in areas where there were gaps in services.

The Child Welfare Research and Demonstration Grants Program, authorized by the Social Security Amendments of 1960, provided a means of financial support for research studies and demonstrations in a wide range of child welfare services, including projects related to the social and behavioral components of mental retardation.

The enactment of the 1963 Maternal and Child Health and Mental Retardation Planning Amendments (Public Law 88-156) provided the basis for substantial expansion of services to mentally retarded children under the maternal and child health and crippled children's services programs. In addition, the amendments included authorization for a new program of special project grants for maternity and infant care to help reduce the incidence of mental retardation caused by complications associated with childbearing. Under these amendments there was also authorization for a new special project grant program for Research Relating to Maternal and Child Health and Crippled Children's Services. The expansion made possible by this new legislation has emphasized strongly increased services to mentally retarded children.

Further progress in providing services to mentally retarded children is occurring as a result of the Social Security Amendments of 1965 (Public Law 89-97). The amendments increased the authorizations for maternal and child health services, services for crippled children, and child welfare services. They also authorized a new program of grants to institutions of higher learning for training of professional personnel for health and related care of crippled children, particularly mentally retarded children and those with multiple handicaps. In addition, they authorized a new program of special project grants to provide comprehensive health care and services for children of school age, or for preschool children, particularly in areas with concentrations of low-income families.

HEALTH SERVICES

Clinical Services

As recently as 1954, maternal and child health activities in behalf of mentally retarded children and their families were extremely limited. Many local public health nurses were reporting suspected mentally retarded children in their caseload, but for the most part they had few or no resources for establishing a diagnosis. Consultation and guidance on how to deal with these children and their families were generally not available. Some children who were functioning below the normal expected level of development were being followed in well-child conferences. However, adequate developmental and diagnostic appraisal was not generally available, nor was continuing guidance to parents once a diagnosis had been made.

Testimony before the House Appropriations Committee in 1957 indicated that the principal needs of the mentally retarded were to find these children early, to provide a complete evaluation, to interpret the findings to parents, and to use the findings as a basis for ongoing help and care. By age groups, the greatest gap in available services was in relation to infants and preschool children. It appeared that these services that were lacking could best be provided within the framework of the maternal and child health program. The basic interests of this program, preventive health services, child health supervision, growth and development, and the fostering of good parent-child relationships -- are also the basic interests of a program for mentally retarded children.

To further development of services for mentally retarded children as part of the maternal and child health program, Congress earmarked $1 million of the increased maternal and child health appropriations for fiscal year 1957 especially for special projects serving mentally retarded children.

The State health departments made use of these funds to establish demonstration programs centering about child health supervision and the problems in growth and development of children who are retarded or suspected of being retarded. The services included diagnosis, evaluation of a child's capacity for growth and evolving together with the parents an individual plan for continuing care and supervision.

The nucleus of the demonstrations usually is a specialized clinical team. This team includes a pediatrician (usually the medical director of the project), a psychologist, a medical or psychiatric social worker, a public health nurse, and, in some clinics, a child development specialist, a speech therapist, and a nutritionist. Other medical consultants such as psychiatrists as well as other non-medical specialists are called upon as needed.

These demonstration projects have not only provided a needed service to retarded children and their parents, but have also allowed the States to demonstrate to local communities the following: 1) how a program might be set up, 2) how cases can be located early, 3) what makes up an evaluation, and 4) what kinds of help can be provided to these children and their families. The accumulation of case data and experience by the group of specialists has also made it possible for these groups to pinpoint other gaps and unmet needs in the State.

Most important, the demonstration projects, combined with the availability of funds from increased appropriations, stimulated the setting up of additional clinics providing specialized services for mentally retarded children. By the end of calendar year 1965 there were 142 such clinics; of these 97 were supported in whole or in part by Children's Bureau funds. It is estimated that the 142 clinics served approximately 46,000 children in calendar year 1965; the 97 Children's Bureau-supported clinics served 30,000 children.

Training of Personnel

The general shortage of health manpower, the increased attention to the health needs of mentally retarded children, and the emphasis on a multidisciplinary approach in caring for these handicapped children have contributed to an urgent need for training professional persons to

work in the field of mental retardation. Training programs have therefore been the concern of the Bureau since appropriations were first earmarked for mental retardation programs.

Training activities have encompassed many approaches: grants for fellowships, support of and participation in institutes, conferences, and other short-term training sessions, consultation on course curriculums, arrangements for clinical experience in mental retardation clinics, and distribution of informational materials to professional workers.

Also, because informational materials are an important training tool for professional workers, the Bureau has operated an exchange of educational materials as a service to mental retardation clinics. Since November 1961, through this exchange, approximately 300 different items have been distributed to each of the mental retardation clinics in the country, including clinics not supported by Children's Bureau funds. Special publications have been developed for professional personnel, and these have been much in demand. Proceedings of institutes have spread the knowledge provided by the institutes well beyond those actually in attendance.

A major portion of the Children's Bureau funds for special projects in the field of mental retardation is now devoted to training projects. Currently, Bureau funds are being used in the training of pediatricians, nurses, dentists, nutritionists, clinical psychologists, social workers, occupational therapists, physical therapists, speech and hearing therapists, cytogeneticists and biochemists, and others.

These activities represent progress in filling the great need for professional persons with a knowledge of mental retardation. Although trained personnel are still in short supply, as additional funds become available it can be expected that training activities will increase. The 1965 legislation will enable the Children's Bureau to expand its present activities for training professional health personnel to work with mentally retarded children. This legislation authorized grants to institutions of higher learning, including university-affiliated centers providing diagnosis and treatment.

Prevention of Mental Retardation

Increasing attention is being given to programs directed at applying existing knowledge to the prevention of mental retardation.

Maternity and Infant Care Projects. The report of the President's Panel on Mental Retardation emphasized the interrelationships of lack of prenatal care, prematurity, and mental retardation. In order to reduce the incidence of prematurity, which would help prevent mental retardation, a recent major emphasis in Children's Bureau programs has been the Maternity and Infant Care Projects, authorized by Public Law 88-156. This law provides for a new authorization for grants to meet up to 75 percent of the cost of projects for the provision of necessary health care to prospective mothers "at risk." These are women who have or who are likely to have conditions associated with childbearing which increase the hazards to the health of the mothers or their infants and whom the State or local health department determines will not receive necessary health care because they are from low-income families or for other reasons beyond their control. In addition, the legislation provides for medical and hospital care for premature infants and other infants at risk.

Late in fiscal year 1964, $5 million was appropriated for this program, and eight projects were approved. For fiscal year 1965, $15 million was appropriated, and for fiscal year 1966, $30 million. By the end of December 1965, 30 projects had been approved.

Phenylketonuria

A second major emphasis in prevention within the past few years has been in relation to phenylketonuria (PKU). This inborn error of metabolism has in the past been responsible for one percent of the population in our State institutions for the mentally retarded. By detecting families with the condition and by placing young infants with the condition on a special diet, mental retardation can usually be prevented. The Children's Bureau has worked with State health departments in developing and trying out various screening and detection programs, developing the necessary laboratory facilities, and assisting States in providing the special diet and followup programs for these families. When the Guthrie inhibition assay method for screening babies before they leave the newborn nursery was developed, the Children's Bureau supported field trials of this test. More than 400,000 newborn babies in 29 States were screened and 39 cases of phenylketonuria were found, an incidence of almost 1 in 10,000.

The Children's Bureau is now urging that all States have a program for screening infants for PKU. Although such programs have been initiated without legislative requirement, in many States laws have been enacted on this subject. As of the end of September 1965, 32 States had such laws, most of them making screening for PKU mandatory.

During fiscal year 1966 approximately $1 million of Children's Bureau funds will be expended for PKU screening and treatment programs. Interest is now shifting to the problems of treatment. Funds have been granted for planning a 5-year collaborative study of treated phenylketonuric children for purposes of increasing knowledge of methods of treatment. As more children with PKU are found, the problems relating to treatment services must receive increased attention.

Interest also is increasing in metabolic diseases other than PKU that lead to mental retardation. The Children's Bureau is currently supporting a study of the clinical application of three screening tests to detect galactosemia, maple syrup urine disease, and histidinemia. Also, support is being given to studies of new approaches to broader screening methods.

Crippled Children's Services to Mentally Retarded Children

Since enactment of the Social Security Act in 1935, the Children's Bureau has assisted the States in providing services to crippled children. Although some mentally retarded children were cared for in these programs prior to 1963, the enactment of Public Law 88-156, providing for increased funds for the crippled children's program, and the earmarking of some of the funds for mentally retarded children in the annual appropriation, has resulted in more attention being paid to physically handicapped retarded children. In some States the definition of crippling conditions is being broadened to include conditions for which services had not hitherto been given. Some children who would formerly have been turned away are now being given service.

A new use to which some of the crippled children's program funds earmarked for mental retardation are being put is cytogenetic or laboratory services. Project grants have been approved which establish such programs as extensions of clinical services at hospitals or medical schools. Projects include chromosome analysis and diagnosis of various medical conditions which may be genetic and which result in mental retardation. On the basis of these analyses, conseling may also be given to parents seeking advice on genetic questions. As of November 1965, 14 such projects had been approved.

An important use of the expanded funds available for mentally retarded children is in providing services for institutionalized children; for example, orthopedic services not hitherto available. Another use is the development of special clinical programs for multiply handicapped children. Ten such clinics were being financed by Children's Bureau funds as of the end of December 1965.

CHILD WELFARE SERVICES

The objective of the child welfare services program for mentally retarded children, like its objective for other children, is to assure that each child receives the care, protection, and services which can enable him to realize his full potential. Child welfare services from which the mentally retarded child may profit include parent counseling, homemaker services, day care services, foster family care, small group care, services to unmarried mothers, adoptive services, protective services, and certain institutional preadmission and aftercare services.

The grants-in-aid for child welfare services authorized by the Social Security Act beginning in 1935 were used in the early years of the program only in a scattered way for retarded children and their families. These funds were used for child welfare services, including foster care for retarded children, and for child welfare workers who gave some service to this special group of children. However, services for many years were limited largely to arranging long-term institutional care for the mentally retarded. Mental retardation was a field shrouded in pessimism and hampered by lack of knowledge. As a result, few families received help that was aimed at the full development of their retarded child.

In 1957 the Children's Bureau began to provide consultation in order to assist States in developing a broad range of specialized social services for mentally retarded children and their families. Their purpose was to provide emphasis, stimulation, and guidance for this important aspect of child welfare services.

Today, all State public welfare programs provide some social services for mentally retarded children. By conservative estimates of the Children's Bureau, 37,200 mentally retarded children receive services from public child welfare agencies. Over 5,500 are served by voluntary child welfare agencies.

Examples of Services

Following are typical examples of State efforts to extend and improve services to the mentally retarded:

A southeastern State has developed a special mental retardation unit which provides a range of public child welfare services in two counties. The effectiveness of this unit is demonstrated

by the results obtained in its work with a group of families who previously had been advised by other sources to institutionalize their retarded child. With support from the unit's social worker, help in using other community resources such as day care, and assistance from the public health nurse in management of the retarded child, 60 percent of the parents were able to keep their families intact. A second unit is now being developed in the same State. Similar achievements are noted in other States which provide family counseling.

Two communities recently initiated programs of homemaker service which have demonstrated the value of this service specifically in families with mentally retarded children. Through this service, an overburdened mother can be given some relief from the constant and full responsibility of day-to-day care of her retarded child. Frequently she acquires new skills from the homemaker which help her in better home management and in her special problems with child care.

Several State public welfare agencies are utilizing day care services for the mentally retarded. Day care programs offer both constructive experiences for some retarded children and necessary relief for their parents. This kind of relief is often the key factor in retention of the child in his own home.

A single county in a western State reports that it is providing foster family care for 100 mentally retarded children. Some children who must be cared for outside their own homes can profit from close interpersonal relationships and respond to the stimulation of family life. Short-term foster care at intervals or during periods of crisis may enable a family to provide adequately for a retarded child at home for the most part. For other retarded children, foster family care permits long-term benefits of family life and community living. Foster family care would be the plan of choice for many children who have been placed inappropriately in large residential facilities. In fact, some States are giving attention to the "exchange" of children between institutional and child welfare services programs to assure more appropriate services for particular children.

Child welfare services also may contribute to prevention of mental retardation. For example, day care or foster care for children from certain deprived homes may be preventive services.

Homemaker service may be preventive in nature when provided to some expectant mothers who need relief from the physical demands of caring for other children, thereby helping them maintain prenatal health. Protective services can reduce child abuse, sometimes a cause of mental retardation. Services to unmarried expectant mothers can assure utilization of proper prenatal services.

Child welfare workers are in a key position for casefinding, assistance with obtaining proper diagnosis, and providing continuity of planning and services consistent with the individual retarded child's need.

Training and Staff Development

To increase the pool of qualified child welfare services staff, all State public welfare agencies have a staff development program including orientation, inservice training, and educational leave. States are urged to use Children's Bureau child welfare services funds for tuition and maintenance grants for educational leave. The staff development programs contribute to the overall increase of child welfare personnel who are better able to serve the mentally retarded.

A most encouraging development is the number of schools of social work which are emphasizing mental retardation. Three schools added full-time faculty in the special area of mental retardation. A growing number of agencies collaborate with schools of social work to provide field instruction in mental retardation.

The child welfare training grants program of the Children's Bureau provides grants to public or other nonprofit institutions of higher learning for training personnel in the field of child welfare, including traineeships to students. Training for child welfare services for mentally retarded children is included in this program.

Despite these developments, numbers of retarded children and their families urgently need child welfare services not now available. Professionally skilled staff, new programs and extension of those in existence are needed. Many States, however, have been unable to finance these special programs because of other pressing priorities.

Relationship With State and Local Child Welfare Services

While the child welfare services program received no special grant funds for mental retardation through the 1963 amendments, these amendments have implications for the field of child welfare:

1. Child welfare must be involved in implementing State plans for the development and coordination of a total array of services for the mentally retarded.

2. State and local child welfare agencies increasingly will need personnel with specialized skills and knowledge to provide consultation and technical advice as they become involved in State planning and implementation of programs for the mentally retarded.

State and local interests and efforts to expand and improve their services to the mentally retarded are stimulated and assisted by the Bureau. Guides and program materials are developed by the Bureau to assist State and local public and voluntary agencies. The Bureau works in cooperation with such national agencies as the National Association for Retarded Children, American Association on Mental Deficiency, American Public Welfare Association, and Child Welfare League of America in developing guides and providing joint consultation to agencies for expanding and improving social services for retarded children. The Bureau works closely with the Council on Social Work Education and schools of social work in planning curriculums for preparing workers for responsibilities in this area. Consultation is given to State and community agencies, organizations, and individuals on the provision of comprehensive services for retarded children with special attention to specific areas of child welfare services. This consultation may be concerned with methods of casefinding, use of diagnostic services, parent counseling, identification of needed research and demonstration and adapting guides to State and local situations. Other service areas, of course, also receive attention: staff development and training, coordination of institutional and community services, and application of the group method to serving retarded children and their families.

The stress placed on families by the mental retardation of a member is so severe, it constitutes a major social problem. The present upsurge of interest and measures for reduction of the handicapped, the alleviation of its impact on the family and the prevention of some cases are reassuring. Yet other factors simultaneously aggravate the problems. Among these are the stresses rising out of poverty, urbanization, automation, and other technological change, and population growth and mobility.

The growing emphasis on community services as a means of combating mental retardation will place increasing demands on child welfare agencies. They will need to step up their programs for retarded children in order to assure the children care and protection and to strengthen family life. Since no State really has developed the needed network of child welfare services for the mentally retarded in terms of range, availability and quality, any optimism about the progress which has been cited must be tempered by knowledge of how far these service programs still must go.

RESEARCH AND DEMONSTRATION GRANTS PROGRAMS

Research and Demonstration Grants

The Child Welfare Research and Demonstration Grants Program authorized by the Social Security Amendments of 1960, provides financial support for special research or demonstration projects in child welfare which are of regional or national significance, and for special demonstrations of new methods or facilities which show promise of substantial contribution to the advancement of child welfare.

Since community support is vital to improvement of child welfare services, an important function of several projects is to develop support through interpretation and communication of the problems that many children face, ranging from shattered families to mental retardation.

The projects relating to mental retardation include: 1) a demonstration to test the feasibility and value of foster home care for deprived mentally retarded children; 2) a demonstration, training, and service project designed to test the feasibility of training and using unskilled personnel as aides to professional personnel in caring for retarded children in the areas of homemaking and child care, physical medicine and nursing care, speech therapy, play activity, and auxiliary maternal care; 3) an evaluation of the quality of a family's decision to institutionalize or not to institutionalize a retarded child; and 4) a study of existing laws and their administration applicable to children suffering from mental disorders, including their commitment, care, and guardianship.

An area of continuing emphasis is development of effective programs for low-income families and children who are most vulnerable to adverse home and environmental influences which retard their growth and development. One such project is based on the parent-training and day care support to insure normal growth and development.

Several projects relating to mental retardation are nearing completion and final reports of the results will soon be available.

Maternal and Child Health and Crippled Children's Services

The purpose of this research grant program, authorized by the Maternal and Child Health and Mental Retardation Planning Amendments of 1963, is to support studies that show promise of making a substantial contribution to the advancement of health programs for mothers and children. Some examples of areas being investigated are: 1) health status of and health services for mothers and children in urban and rural communities; 2) new approaches to providing maternity health services; and 3) methods of increasing the effectiveness of child health programs especially services for school-aged children and for mentally retarded children.

The studies are all in applied research and are classifiable as epidemiological, demographic, operational, administrative, or evaluative. The grants may be awarded to institutions of higher learning, and other non-profit agencies or organizations engaged in research or maternal and child health or crippled children's services.

Recognizing the acute shortage of competent research personnel knowledgeable in the areas of maternal and child health and mental retardation, the Children's Bureau is developing "programmatic research" projects. This type of research is a long-term commitment in a specific aspect of a research program, entailing studies in depth of two or more projects with personnel knowledgeable and career-directed in the problem areas.

In the area of mental retardation, projects have been funded which will study ways to improve amounts and quality of prenatal care. These are an effort to reduce the occurrence of prematurity and as a means of preventing mental retardation due to these causes. Several projects supported in various schools of medicine have as their objective an evaluation of methods for screening children for metabolic and other inherited diseases which can lead to mental retardation. They also seek to develop procedures for screening preschool children for neurological damage and psychological deviancy.

In one project, a major step may be achieved in alleviating the critical shortage of trained professional psychologists. This project will test, in selected mental retardation clinics throughout the country, a plan for utilizing nonprofessional personnel.

Another major study that has been funded proposes to uncover every case of mental retardation in a well-defined population. The prevalence of mental retardation and its relation to social, economic, and demographic characteristics of the individual and his household will be investigated in the hope of uncovering etiological relationships.

A study will be undertaken toward redirecting school nursing services in culturally deprived neighborhoods with a concentration on kindergarten pupils. This project will include: 1) routine home visits, 2) leading parent education study groups, 3) and providing more intensified followup of the mentally retarded and the neurologically handicapped.

Final reports on the results of research financed under this program will be received beginning in fiscal year 1967.

PLANS FOR THE FUTURE

During the next few years, it is anticipated that the following developments will take place in mental retardation activities of Children's Bureau programs:

Continued emphasis on prevention of retardation through improved prenatal services, care of premature infants, and improved methods for the detection, diagnosis, and treatment of infants with metabolic disorders which result in retardation.

Expansion of community programs for mentally retarded children to provide more and improved diagnostic, evaluative, and preventive health services.

Continued emphasis on encouraging development of improved child welfare services for mentally retarded children.

Development of additional clinic centers for the evaluation and treatment of multiply handicapped children who have physical handicaps and are also mentally retarded.

Expansion of genetic and biochemical laboratory services as an extension of mental retardation clinic services and increased attention to genetic counseling services.

Staffing of university-affiliated centers for mental retardation to increase the supply of trained professional workers; additional training projects for professional and subprofessional workers.

Encouragement of research and demonstration projects concerned with improvement of programs and services for retarded children.

Increased preparation and distribution of materials for technical persons and for the public.